The Importance of Language and Messaging in Psychological Treatment for Functional Neurological Disorder in Children and Adolescents

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ABSTRACT

The treatment for Functional Neurological Disorder (FND) is complex and often includes a multidisciplinary approach. One core intervention is the psychological approach through therapy, typically drawing on evidence-based practices and incorporating biopsychosocial themes. This article highlights components of the psychological approach that are integral to treatment. While therapeutic concepts are explained in the context of treatment at the Hasbro Children's Partial Hospital Program, they are applicable to any setting. This article will review the importance of psychoeducation and the importance of language and messaging when talking with patients and families. Additionally, key concepts of emotional expression and distress tolerance, which are central to psychological treatment, are discussed. Finally, this article highlights the role of the family and the integral part it plays in the treatment for FND.

KEYWORDS: Psychological Therapy, Psychoeducation, Functional Neurological Disorder, Family, Pediatrics

CASE

While inpatient, BH and her family were provided psychoeducation about the diagnosis of FND, and treatment focused on improving essential functioning. Once BH was able to make some progress with her functioning, she was then admitted to a partial hospital level of care at the Hasbro Children's Partial Hospital Program (HCPHP). Multidisciplinary team members included a psychologist, psychiatrist, pediatrician, physical therapist, occupational therapist, nurses, dietitians, teacher, and milieu therapists.

- What would be important to assess when beginning psychological treatment?
- What themes in therapy may be explored?

INTRODUCTION

An integral component of treatment for Functional Neurological Disorder (FND) is the psychological approach.[1] However, research is limited on evidence-based psychological treatment for this disorder.[2,3] Additionally, the complexity of presenting symptoms and contributing factors require a multidisciplinary treatment approach that may include psychopharmacological medication and rehabilitation therapies, depending on the nature of symptoms.[4] There are also components of different psychotherapies (e.g., cognitive behavioral therapies, mindfulness, psychodynamic therapies) that can be helpful in the treatment of FND, as there is no singular evidence-based treatment that is applicable to all case presentations. In higher-level, integrated care settings such as the Hasbro Children's Partial Hospital Program (HCPHP), effective treatment approaches include drawing from established evidence-based practices, working with a multidisciplinary team, and significant involvement of the family.[5,6,7] Before diving into targeting symptoms, a crucial first step in therapy is providing psychoeducation about FND and reaching a level of acceptance of this diagnosis.[8]

PSYCHOEDUCATION, LANGUAGE, AND ACCEPTANCE

Imagine experiencing physical symptoms, getting bloodwork done, completing imaging studies, and then hearing from a doctor that there is a definitive diagnosis that accounts for all of the symptoms. Being able to review objective data/concrete results together with the doctor and learn about the established protocols of medication and lifestyle interventions to treat the diagnosis is often reassuring to patients and families. However, with FND, education focuses on helping patients and families make sense of a less concrete diagnosis with unusual symptom presentation, often with doubt around the diagnosis expressed by patients, families and providers, and concern of a missed underlying medical explanation.[9] Additionally, family, cultural, religious or foundational beliefs may influence acceptance of psychological diagnoses.[10] With FND, even those who are more accepting of a psychological diagnosis may struggle with understanding the concepts due to the complex nature of the disorder without structural pathology. This leads many to seek extensive medical evaluations even after a diagnosis of FND is made.[11] Any parent witnessing their child experience acute loss of functioning (e.g., paralysis) or seizure-like activity would understandably be alarmed and want a concrete answer that is supported through abnormal test results. One contributing factor to patients' and parents' struggles to accept a diagnosis of FND is messaging from

medical professionals. Unhelpful phrases or framing may be that "nothing is wrong," which can be interpreted as "it's all in your head" or that symptoms are not "real" and that they are "psychological."[12] Terms like "psychogenic" or "behavioral" or "pseudo" (in the case of non-epileptic seizures) have frequently been used and unintentionally reinforce stigmatizing messages.[9] It is crucial to support diagnostic acceptance in patients and families to move forward with treatment as a main focus will be on psychological interventions. Using terminology such as "functional" instead of "psychological" can be helpful and less stigmatizing. Additionally, using relatable language and comparisons, such as describing FND as a "software not hardware" problem with symptoms occurring when the "computer crashes," may be an easier concept for kids and families to grasp.[13] If there are strong seeds of doubt, this will ultimately hinder the therapeutic process and become a distraction and barrier to progress. Transparent conversation with patients and families around their ambivalence can be helpful in forming a trusting therapeutic relationship.

THE MIND-BODY CONNECTION

How are the concerning, and sometimes bizarre, symptoms of FND explained in a way that is helpful for families to understand and accept? The answer is to focus on the concept of the mind-body connection. Most people can readily give examples of ways that their mind and body are connected. People's hearts beat fast when scared; bodies sweat when nervous; headaches emerge when stressed; and blood pressure spikes when angry. Kids hear the phrase "butterflies in your stomach" to explain the feeling of stomach discomfort before performing or starting something new. Adults and kids alike can relate to gastrointestinal discomfort and needing to use the bathroom when they feel nervous. Even though these physical symptoms are rooted in emotions, they are not usually perceived as "being in your head."

So, why are these examples easier to understand and accept? One reason is that the physical symptoms of FND often seem more serious and, therefore, concerning. The same process occurs where there are physical manifestations of underlying psychological emotions, though the physical symptoms of FND present in neurological ways, such as disruptions in movement, speech, vision, hearing, memory, and consciousness.[12] It is important for medical professionals to keep in mind that most people have never experienced such symptoms and therefore do not readily integrate this concept into their understanding of a mind-body connection. Additionally, it can be helpful to conceptualize FND as a miscommunication between the brain and body, where the brain needs to be "retrained" to make the appropriate connections. An example most can relate to is a scenario where a person feels nauseous after eating something and then has the experience of feeling nauseous in the future when just thinking of or seeing that food. This illustrates how there can be a physical response without an organic cause because of a connection between the mind and the body and how this connection or signal needs to be retrained.[14]

Another component in helping families understand and accept the mind-body connection in FND is to address the role of stressors.[12] Some presentations of FND have clear precipitating and/or perpetuating stressors. Examples of this could include a child who had an illness or injury that seemed to disrupt how the brain and body send and receive signals or a child who experienced some psychological trauma and historically struggles to identify or express emotions and has never talked about the experience. FND used to be known as Conversion Disorder, as this concept of psychological distress being converted into physical symptoms was at the core of this diagnosis.[12] However, the more recent name change to FND in the *Diagnostic and Statistical Manual – 5th Edition* recognizes that not all individuals have identifiable stressors or trauma, and, therefore, a more encompassing diagnostic term was developed.[15] While there may not always be a specific stressor that a family can identify as a trigger for the symptoms, it's important to help patients and families understand that cumulative "little" stressors or life pressures can impact the mind-body connection by activating or dysregulating one's stress-system and changing the functioning of neural networks.[16] Things like pressure to do well or keeping up with the demands of activities and friendships can be experienced as stressors even if the child does not identify them as stressors.[12] Going back to scenarios most people can relate to can help families understand this. Most can appreciate how even positive life changes can have elements of stress, such as a move, an addition to the family, or planning for a vacation. Another relatable scenario is to feel prepared for a test or performance and not feel nervous yet still wake up with diarrhea that morning. The mind-body connection is a powerful phenomenon!

PSYCHOLOGICAL FOCUS

Once the diagnosis of FND is better understood and accepted, treatment can start to delve into other psychological components of intervention. Review of a decade of studies highlighted a common thread of a biopsychosocial approach, which entails taking into account biological, psychological, interpersonal, and school/social-contextual factors, in the treatment of children and adolescents with FND.[16,17] Because of the often heterogeneous and complex nature of presentations, including symptom severity, psychological comorbidities, and stressors, treatment may pull from a variety of interventions. These could include Cognitive Behavioral Therapy (CBT) or CBT-informed psychotherapy, Retraining and Control Therapy (ReACT), as well as components of other theoretical models such as Psychodynamic Therapy and Mindfulness Based Therapy.[18,19]

At the HCPHP, psychological interventions draw from a range of established therapies. Therapy focuses broadly on increasing emotional awareness as well as improving emotional expression. It also aims to build skills in recognizing cognitive distortions and engaging in thought-challenging. Patients work on generating and utilizing healthy distress tolerance skills to regulate their stress-system. Other themes of therapy include normalizing functioning through behavioral goals and expectations, exploring roles symptoms are playing in the family, and working with families on how to empower their children and not the illness.[5,6,7,20]

A core emphasis of treatment at the HCPHP is emotional expression. Therapy encourages patients to talk about their feelings and what they find challenging. It may include topics they feel strongly about or ones where they feel conflicted or unsure. Patients have opportunities to explore and express emotions in different treatment modalities, such as individual, group, and family therapies, as not everyone is comfortable doing so in a particular setting. Emotional expression is encouraged through conversation, artwork, journaling, or other creative ways that patients identify. Therapy aims to help patients generate and reflect on topics they can relate to an emotional experience, such as worrying about illness/death in the family, academic stress, change in schools or peer groups, high demands of performing in activities they love, parental discord, and struggles with identity.

Another core focus of therapy is the concept of distress tolerance and use of coping skills. Many patients presenting to a higher level of care experience a significant disruption in their lives due to FND symptoms, including not being able to attend school or engage in other activities. As part of therapy, there is a focus on learning mindfulness or grounding strategies that help to stay in the moment and feel connected to surroundings, such as breathing in and out slowly while tracing fingers or focusing on surroundings and finding five things that can be seen, four that can be touched, three that can be heard, two that can be smelled, and one that can be tasted. These techniques are particularly helpful when feeling as though one's body is out of control. Practicing relaxation techniques, such as deep breathing or progressive muscle relaxation, is another component of therapy. Developing and using coping skills that can help tolerate psychological or physical discomfort by "riding the wave" until the distress lessens is also a central part of therapy. Patients work on developing cognitive strategies of self-talk/coping statements and thought challenging that can help them recognize the interconnectedness of thoughts, feelings, and actions as a tool to exercise thinking in a more adaptive way. For example, creating coping cards with statements such as "I feel like I can't walk and I know my body is strong" can be helpful. Working on recognizing cognitive distortions or thinking traps, such as "jumping to conclusions" or "overgeneralizing," and identifying emotions and actions that are affected by accepting these thoughts versus challenging them is another integral part of therapy. An overall goal is to not focus on whether or not an FND episode or symptom occurs but rather to practice these strategies so that, overtime, the body will not need to show distress in physical ways and also becomes "retrained" in terms of the mind-body connections.

ROLE OF FAMILY

As with most psychological treatment for youth, the family is an integral component of treatment for FND as parents are the experts on their children and are uniquely positioned to impact and promote progress.[5,6,7,21,22] First, it is essential that families learn how to respond when symptoms or episodes occur. Sometimes this is referred to by patients as going into "FND mode," which means that caregivers are supportive but do not overly attend verbally or physically. It is in a parent's nature to want to reassure and "fix" things when they see their child in distress; however, giving too much attention to the symptoms by frequently questioning how the child is feeling or talking to and hugging them in the midst of symptom flares can have the opposite effect, actually reinforcing FND.[16] Second, the concept of "externalizing the disorder" by talking about FND as a separate entity that everyone is pushing back against can be a powerful tool and help patients feel less like they are battling themselves or that others are blaming them for symptoms. Third, a key focus of family work is supporting caregivers to maintain normal daily activities and expectations.[14,20] It is not unusual for FND symptoms to result in patients getting physical support to move around and, consequently, a reduction in expectations to participate in activities. However, by doing this, symptoms of FND are being accommodated and, in turn, give FND more power, which is counterproductive to treatment progress. Fourth, families can support their children by encouraging them to express difficult emotions, being open to talking about stressors, as well as by modeling these behaviors for their children. This may not be something that families are used to or comfortable doing but is an essential part of the therapeutic process. Fifth, families need to be self-aware of their own reactions to FND symptoms and the language they use with their children. Negative reactions, language, or messages expressing anxiety, frustration, and hopelessness can worsen FND symptoms as they can contribute to decreasing self-worth and confidence. Similarly, using language like "it's not real," "it's in your head," or "you are doing this on purpose," can be received negatively by children and hinder progress. Most aspects of FND are unconscious, though symptoms can exist on a continuum of awareness. As with many behaviors, over time symptoms can become associated with secondary gains that then influence patterns of behaviors. This does not mean that children are intentionally or consciously exhibiting a symptom but rather adapting behaviors based

on reinforcement. Finally, it is important for families and patients to understand that it takes time for symptoms and episodes to consistently decrease even though patients are better at sharing thoughts and feelings, using strategies to tolerate distress, and retraining their mind-body connections. Throughout this process, it is common for symptoms to shift in presentation, which can be alarming to families but is framed as part of the treatment journey. Understanding that the focus of treatment is not on whether symptoms or episodes occur but rather on the child's efforts to function despite symptoms and the family's ability to adaptively respond to their child is an important aspect of treatment.[5,20]

SUMMARY

FND can be a difficult diagnosis for patients and families to comprehend and accept. It is important to be cognizant of how one frames this diagnosis to a child, adolescent, and family. Psychoeducation that focuses on the mind-body connection, messaging that physical symptoms are real, and exploring connections between feelings, stressors, and FND symptoms, are all essential to the therapeutic process. Psychological treatment of FND draws from a variety of treatment paradigms and emphasizes a biopsychosocial approach to address the complexities that are often found in FND presentations. Overall, therapy aims to target emotional awareness and expression, facilitate use of strategies to help regulate the stress-system, promote positive functioning, and ultimately retrain the mind-body connection.

CASE UPDATE

During the course of the partial hospital admission, BH's FND symptoms improved but with periods of regression. This led to questioning by BH and parents as to whether there could be anything else accounting for her symptoms. Psychoeducation continued to be an important thread of treatment in order to help BH and family make progress and not become distracted by "what ifs." This was particularly important in family work, as ultimately parents' ability to remain calm and confident in their response to symptom variability and their messaging to BH about her functioning was a crucial factor in her progress.

It was also helpful for the family to increase their awareness of life pressures and family dynamics and how BH experiences them. Parents worked to share their feelings more, which ultimately helped BH move from claiming "I have no feelings; I am a robot," to being able to express her emotions more productively.

Themes of therapy also centered on helping BH identify and challenge automatic negative thoughts around her symptoms and functioning and reframe them to highlight how she was working on retraining her mind and body (e.g., "I feel like I can't walk," and "I can practice taking a step"). She worked on distress tolerance skills that focused on grounding and mindfulness strategies for when her body didn't feel in control. BH also worked on earning different privileges for meeting functional milestones, such as progressing from using a walker for ambulation to using a cane.

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